



Conducting Focus Groups to Inform the Michigan Department of Community Health Sickle Cell Disease Strategic Plan



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Learn more about Michigan Hemoglobinopathy Quality Improvement Program:

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I. Overview of Sickle Cell Disease

Sickle cell disease (SCD) is the most commonly inherited blood disorder affecting approximately 90,000 Americans and 1 out of 500 African-Americans.¹ Approximately 2,800 individuals with SCD live in Michigan. SCD is caused by a genetic mutation in hemoglobin, which predisposes red blood cells to become rigid and misshapen, or “sickle”-shaped. SCD is a mutation in the gene for hemoglobin and a lifelong condition complicated by acute and chronic medical problems, which can be life-threatening and disabling. Common complications include episodic severe pain, chronic hemolytic anemia, increased vulnerability to infection and multi-organ damage.² SCD adversely impacts the physical, emotional, social, and vocational lives of both the individuals affected and their families across the lifespan.

The three main types of SCD are:

- **Hemoglobin SS disease** (also called sickle cell anemia)

This is the most common type of SCD. In hemoglobin SS disease the body destroys the sickled cells. When this occurs, the number of red blood cells is lowered. This results in anemia.

- **Hemoglobin SC disease** (also called sickle cell hemoglobin C disease)

People with this condition have fewer cells that change from a round shape to a sickle shape. In people with hemoglobin SC disease, one parent has sickle cell trait and the other parent has hemoglobin C trait. Hemoglobin C is another type of abnormal hemoglobin.

- **Sickle beta thalassemia** (also called sickle cell thalassemia disease)

This is also a form of sickle cell disease. Cells may have a tendency to change from a round shape to a sickle shape. In people with sickle beta thalassemia, one parent has sickle cell trait and the other parent has thalassemia trait.

II. Background

The Michigan Department of Community Health (MDCH) has partnered with the Sickle Cell Disease Association of America-Michigan Chapter (SCDAA-MI) since 1987. The SCDAA facilitates follow-up care of babies identified through Michigan’s newborn screening program (NBS) who are diagnosed with sickling conditions. In September 2014, the MDCH Division of Lifecourse Epidemiology and Genomics collaborated with the SCDAA-MI to conduct five focus groups comprised of individuals living with SCD, caregivers, and parents of children with SCD. Patient Advocates from the SCDAA-MI recruited focus group participants. Sessions were held in Detroit, Saginaw, Lansing, Benton Harbor, and Grand Rapids at the SCDAA-MI satellite offices. Focus group data was gathered, analyzed, and subsequently presented at the MDCH Sickle Cell Disease Strategic Planning Meeting, held on October 13, 2014.

Focus groups were conducted as part of an MDCH initiative to design a comprehensive public health plan to address the needs of individuals (children and adults) with hemoglobinopathies, particularly SCD. The purpose of this study was to understand the views of populations affected by SCD and to identify strategies to improve SCD across the lifespan. In particular, program staff wanted to understand how individuals living with SCD and their caregivers dealt with transition care from pediatric to adult providers; use of clinics and emergency rooms for

pain episodes; barriers to employment or education; community and educational resources; financial barriers to care; mental health concerns; use/non-use of hydroxyurea; and transportation.

Sessions took approximately 1.5 – 2 hours to complete and no identifiable information was collected from participants. Discussions were led by a neutral facilitator with pre-developed questions and audiotaped discussions were later transcribed by MDCH staff.

III. Focus Group Questions

The following table is a list of questions used for focus group dialogue, along with “probes” to stimulate discussion.

Table 1. Focus Group Discussion Questions & Prompts

Key Questions	Sample of Question Prompts
1. What community resources have you found most helpful in managing your/your child’s diagnosis of sickle cell?	What community resources would you like to see created for individuals with sickle cell disease?
2. What gets in the way of your/your child being able to attend scheduled appointments for sickle cell care?	If needed, specific issues might be brought up like cost, transportation, child care, time off from work/school, other obligations, etc.
3. Have you talked with anyone about using a medication called hydroxyurea as treatment for your/your child’s sickle cell disease?	Was it recommended that your/your child take hydroxyurea? What factors influenced your decision to take/not take this medication?
4. When you/your child need immediate care because of pain episodes due to sickle cell disease, where do you usually go for care?	Have you/your child ever used a day treatment center (or emergency room) for pain management? What was this experience like, and how was it different from the emergency room? If you do not use a day clinic regularly for care, what barriers prevent you from doing so?
5. What has been done to help prepare you/your child for transitioning from pediatrics to adult care for sickle cell disease?	What should health providers (doctors, nurses, social workers, child life specialist, etc.) be doing to help prepare individuals to transition to adult care?
6. Is there anything else you would like to tell us about sickle cell disease that we haven’t discussed?	

IV. Focus Group Participants

Focus group participants included individuals with SCD, family representatives who care for them, and parents of minor children with SCD. The individuals and family representatives were ages 18 and above, primarily African American. SCD is recessively-inherited mainly in populations with African descent and affects approximately 1 in 500 African-American babies and 1 in every 36,000 Hispanic-American babies.³ SCDA-MI Patient Advocates attempted to recruit other racial and ethnic minorities whenever possible. Children under age 18 were excluded from the study as their parents/guardians were responsible for providing opinions about their experience with SCD. In total, there were forty-three individuals that participated in the sessions; eighteen participants were adults living with SCD; twenty-one participants were parents of children with SCD; 3 caregivers attended; and one MDCH nurse practitioner participated.

V. Participant Compensation

In lieu of travel reimbursement and payment for their time participating in a 1.5 -2 hour meeting, participants were given a \$25 gift card to express appreciation for their input. The cards were purchased in batches from Walmart and Meijer by the Children's Special Health Care Services (CSHCS) Family Center and the SCDA-MI. Gift cards were distributed in-person following the meetings.

Table 2. Participant Description

Meeting Locations & Dates	# of Adults living w/SCD	# of Parents of children w/SCD	# of Caregivers	Total
Detroit (9/10)	4	2	-	6
Saginaw (9/16)	6	8	1	15
Lansing (9/22)	3	5	1	9
Benton Harbor (9/23)	3	3	1	7
Grand Rapids (9/30)	2	3	-	6*

**One MDCH Nurse Practitioner participated in Grand Rapids focus group session*

Table 3. Participant Ages

Ages	Child of Parent	Adults
0-5	2	-
6-10	5	-
11-18	8	-
19-30	5	8
31-50	-	3
51+	1	7

**Caregivers and MDCH Nurse Practitioner age not included*

VI. Focus Group Findings

Some information has been redacted from participant quotes in order to provide anonymity to hospitals and physicians.

a. Question One Responses: What community resources have you found most helpful in managing your/your child's diagnosis of sickle cell?

Most Helpful Resources	Additional Needs
SCDAA-MI	Psychosocial support
Children's Special Health Care Services	More attention and funding for SCD
Hematologist/Clinics	CSHCS Coverage beyond 21 years of age
Transportation Services (ex. Spectran, Medicaid, American Red Cross)	

Summary

Focus group participants reported the SCDAA and Children's Special Health Care Services (CSHCS) as the two community resources they found most helpful. Additional community resources recognized were: hematologists/clinics and transportation services such as Spectran, Medicaid, and The Red Cross. Spectran is a service provided by CATA, which is only found in the Lansing area. The most frequent request was for CSHCS to cover SCD patients beyond the age of 21.

Participant Quotes

1. "Adults with sickle cell teach children who have it. They go to their homes and pick them up and bring them to the Center." - Reference to Project Enrich
2. "I have 3 children with special needs and do not get any resources, even though I adopted a child. Other states get more resources."
3. "The services across the board, from the clinics to the hospital rooms, we need more money. For years I have been told we don't have the money to do that."
4. "Project Enrich allows for children to get one on one attention and provide them with adequate education and what it means to live with sickle cell. It helps them to not fall behind in school."
5. "(Patient Advocate) is like my big sister. She gives me information and I want to learn."
6. "My son was diagnosed at birth. I've lived in 5 different states and (city) is very far behind. When I lived in California, all of the doctors he needed to see were in one location. Now I have to take him to all different doctors. It's not streamlined."
7. "CSHCS is very helpful with billing issues."
8. "I feel like I'm penalized for making good choices and my husband having a good job because I don't qualify for CSHCS or any similar programs."
9. "My daughter is in her senior year of high school and she is just now getting an IEP. Since having an IEP in place, she gets extra time on tests now and extra time for homework."

b. Question Two Responses: What gets in the way of you/your child being able to attend scheduled appointments for sickle cell care?

Limits Attending Medical Appointments
Transportation (the weather, lack of transportation, cost)
Scheduling
School & Work

Summary

In response to being asked what limited participants from attending scheduled appointments, participants reported transportation, scheduling, and school/work as having the biggest impact. Transportation was reported as an issue in the winter months when the weather is bad and participants cannot travel far distances to attend scheduled appointments. This was especially difficult for Saginaw SCD participants because the closest transfusion clinic is located in Ann Arbor. Focus group participants also cited the difficulties of keeping employment while attending multiple appointments. Employer empathy and understanding seemed to be an issue.

Participant Quotes

1. "My son missed a lot of school when it got cold out. The school almost penalized him for missing school, but he was able to graduate."
2. "The clinics need better communications."
3. "Having only one hematologist in the area makes it difficult when he goes on vacation or is unavailable."
4. "In (city) I'm just told who I need to call. It's not even really a referral."
5. "There needs to be more education in schools about sickle cell. My son kept having accidents in school because his teacher wouldn't let him go to the bathroom."

c. Question Three Responses: Have you talked with anyone about using a medication called hydroxyurea as treatment for your/your child's sickle cell disease?

Knowledge of Hydroxyurea
Majority reported knowledge of hydroxyurea
Most participants discussed hydroxyurea with their physician or patient advocate
Many expressed concern over dosage levels, adverse side effects, and insurance coverage
Some participants reported positive results, while other reported adverse results (i.e. nausea, weight gain, hair loss)

Summary

Hydroxyurea is traditionally known as a chemo therapeutic drug because of its use in treating leukemia and different types of ovarian cancer. Hydroxyurea has also been shown to decrease the number of pain crises in sickle cell patients. There were mixed responses from focus group participants pertaining to hydroxyurea. The majority of participants reported they had at least heard of the drug through discussions with a physician or patient advocate. Participants reported concern over varying dosage levels, adverse side effects, and insurance coverage. Some participants reported overwhelmingly positive results, while others reported adverse results (i.e. nausea, weight gain, hair loss).

Participant Quotes

1. "I don't get a lot of pain crisis. My fear at the time was I want to live long. My grandfather is 93 and I want to live as long as him. I had concerns (about hydroxyurea) because of the side effects like gaining weight and loosing hair. Talking with (doctor) helped me look at it not as just pain management, but more as longevity."
2. "How many milligrams do I have to take a day?!"
3. "My son was going to the hospital frequently. His doctor said that he was a good candidate for hydroxyurea. He had some adverse effects early. Now his pain crises are far less frequent. He still gets some headaches, but we're working on it."
4. "My daughter does great on hydroxyurea; she hasn't had a pain crisis since December. She has a GloCap that reminds me to give her the medication. Before she took the drugs, she had crises every month."
5. "There is a 1% chance of developing cancer with hydroxyurea, and I'm not having that."
6. "I've never heard of hydroxyurea. What is that?"

d. Question Four Responses: When you/your child need immediate care because of pain episodes due to sickle cell disease, where do you usually go for care?

Medical Care Facilities Utilized for Pain Episodes
Emergency departments are primarily used as first choice
Pains is managed at home and the emergency department is used as a last resort
Participants expressed a need to develop and implement an emergency room protocol to reduce wait time until first dose of pain medication
Increased education for physicians treating patients
More patient empathy

Summary

Focus group participants reported primarily using the emergency department (ED) as their first choice when asked where they seek care for pain episodes. Many participants also reported to managing their pain at home and the ED is used as a last resort. The need for an ED protocol

specifically for SCD was discussed at multiple focus group sites. Participants also cited a need for increased physician education on SCD and the need for a greater level of empathy for the pain SCD patients endure during pain crises.

There were also multiple discussions about the stigma that came with being an African American with SCD. Participants reported doctors only viewed them as drug-seeking, and subsequently did not provide the necessary care that SCD patients require. Focus group participants expressed frustration with ED physicians because of their lack of understanding of SCD and refusal to administer high enough dosages of narcotics to treat SCD pain.

Participant Quotes

1. "They (emergency room staff) sent me home because they thought I was a drug addict. I was having a pain crisis and I took morphine and waited an hour and it didn't work. I went and got blood work and they said you have morphine in your system. I said yeah because I was in pain. They sent me home. I came back and the hematologist recognized my pain and they admitted me."
2. "Doctors see my list of medications and won't treat me. I went a whole month without the meds I need."
3. "He (emergency room doctor) messed up 10 times on me (attempting IV)."
4. "They (ED staff) ask me the same questions every time. They should be able to have those questions in the computer."
5. "I had a bad pain episode and I paged day treatment and they called me back and said to come in. I was able to bypass ER and got immediate treatment and I was able to get the care I needed."
6. "I took my son to Chicago for his birthday one year and he had a crisis. We sat in the ER for hours because they didn't know what to do and how to treat it. I sent a letter to the head doctor because I was so upset about how long it took for us to get seen."
7. "(In the emergency department) You may get someone that's experienced, and you may get someone who's not."
8. "There's constant judgment in the emergency department."
9. "My issues are with the ER. The lack of knowledge of the medical professionals about the disease is appalling. On a scale of 1 – 10, it's like a negative 5. They talk to you like you have no education; like you are some kind of perceived group and you have no sense at all. It's a consistent issue. I don't know if it's medical school, I don't know. If you have a comprehensive center, you should be very well versed. It's very poor treatment of the disease in the first place."
10. "My son knows where it's easier to get a vein. They don't give him enough respect because they think he doesn't know his own body."
11. "They (emergency room staff) don't know very much and what they know is wrong."
12. "Why can't there be a greater degree of education for people who are going to work in a hospital in an area with a higher concentration of a specific disease like sickle cell?"
13. "There should be a standard protocol for treating sickle cell patients in the emergency department."

14. "Some doctors are justifiably afraid to treat sickle cell patients. It is a labor intensive disease and sickle cell is so multi-symptom."
15. "When we lived in New York, there was an emergency department protocol in place. My daughter received great care immediately. I wonder if this is a Michigan or Midwest thing. All she does in (city) is wait to get care."
16. "They just assume because of their skin color that they are addicted to drugs."
17. "I use the Short-Stay instead of emergency department. I can call them at any time and they will get me in that day. When I get there, they hook up my IV fluids right away. There's a bed and room ready because they have standing orders and my doctor has already arranged the orders when I get there. This is something I discussed with my doctor and it was set up. It takes 5 hours total. My pain meds are ready. Nausea meds, pain meds, and Benadryl are already. A chest x-ray is ordered just in case as well. They (short-stay) treat other illnesses and ER cases there as well, not just sickle cell disease. If my blood work comes back and it's below 6, they have instructions to transfuse 2 units of blood. There are only nurses that work there and they just fill the doctors' orders."
18. "Since I've been going to Short-Stay, I don't get admitted to the hospital as often."
19. "Sometimes you have to be firm with the doctors. They are looking at it from a medical standpoint, not from a parent's standpoint."
20. "My son's immune system is weak so I try to stay away from the ER with him."
21. "(Hospital) is stepping up their game. They've gotten more knowledgeable since I started going there."

e. Question Five Responses: What has been done to help prepare you/your child for transitioning from pediatrics to adult care for sickle cell disease?

Transitioning Preparation for Pediatric to Adult Care
Most participants reported good care as children, but their care declined as adults
Several parents with minor children were unaware of transitioning
Participants expressed the need for development of transition plans and protocols for children at an earlier age.

Summary

Transition of care was a significant issue at all 5 focus groups. Participants reported having a high degree of care when they were children, but once they became adults their level of care significantly declined. Multiple parents with children under the age of 18 expressed concern about the transition of care, and some did not know there was a care transition at all. There were extensive discussions about the need for more transition readiness planning and policy development at an earlier stage

with pediatricians and/or hematologists. SCDA-MI patient advocates also needed to play a more prominent role in facilitating the transition of care.

Participant Quotes

1. "Knowledge is power."
2. "Sometimes it's all about getting the exam done and no attention is paid to children. This is an important part of transitioning from childhood to adulthood. Patients must be able to give their own patient history in order to receive the care they need. There is a resident at (hospital) now advocating for the transition between childhood and adulthood. More focus is put on children being able to report their own patient history and knowing where to go for care and how to make an appointment."
3. "One of the big goals is to help people who have sickle cell disease be able to make an educated decision on whether they want to have children or not."
4. "Maybe patients that don't have a strong family support could have a patient advocate to come in and help talk for themselves."
5. "I think something should be put in place where if they (patient) are having a crisis and don't have any support they (patient) could call someone and have them be their patient advocate at the hospital."
6. "When I was a child all of the doctors and nurses felt bad for me having sickle cell disease. They were nice, thought I was a cute kid. Once I hit 18, all of that stopped and I was treated totally different. That's when they started saying I was a drug addict and there was nothing they could do for me."
7. "Once you leave peds, you are totally on your own."
8. "No one has ever talked to me about transitioning. (Patient Advocate) helps me now."
9. "I'm teaching my daughter to be her own advocate."
10. "My son is 19 but still sees his pediatrician. Who can I talk to about transition because he's old enough now?"
11. "I don't understand why there is not a protocol already in place to help people automatically transition from peds to adult care. Why don't they just transfer his records and history to someone in adult care?"
12. "20ish boys do not like to talk about sickle cell disease. I wish there was some kind of support group where my son can talk to other people."
13. "When I was transitioning my care, I had to make a lot of calls that I was not prepared for."
14. "My mom would call the hematologist when I was a child and then that person would call the ER and get them in the room right away. Now that I'm an adult, I don't know what to do as much because my mom did everything for me before."
15. "Transitioning requires a relationship between parent, patient, and provider. Preparing your child is essential."
16. "I feel like I was handed to the wolves. When my cousin turned 15, two hematologist started seeing her together. An adult and pediatric hematologist. Then the pediatric hematologist just faded out and it was a seamless transition."

f. Question Six Responses: Is there anything else you would like to tell us about sickle cell disease that we haven't discussed?

Additional Items of Importance
Lack of availability to purchase life insurance coverage for persons with SCD
Racial disparity
New medications for treating SCD
Additional physician and nurse training, particularly for the emergency room

Summary

Focus group participants had a variety of different responses about other things that they wanted to report pertaining to SCD. Responses included: lack of life insurance coverage, racial disparities compared to other blood disorders, questions about new drugs on the market, the need for additional physician/ nurse training, and much more. The focus group facilitator did have to point out that MDCH does not have much control over some issues, specifically life insurance coverage, for example.

Participant Quotes

1. "The American Academy of Pain says you should have pain meds within a certain period of time and that amount of time is almost double for people with sickle cell disease."
2. "Sickle cell patients are labelled as drug addicts."
3. "When my son starts a new grade, I take literature about sickle cell disease to the principal and teacher. I meet with them to talk about how sickle cell disease works. I give them a documentary to watch too."
4. "No one pays attention because we're black people."
5. "We're just the step-children of disease, certainly blood diseases."
6. "My son hides his pain. He is 12 years old. They think he wants to miss school. He wants to go to school."
7. "Even someone that's a drug addict and has sickle cell disease is in pain. They still need medications."
8. "Sickle cell disease is not important – they put us at the bottom. I am going to keep fighting until we get everything we need."
9. "I'm happy with my doctor. He doesn't show any racism to me or my daughter. He doesn't have that god complex."
10. "When I went to (city) I got care immediately. This does not happen in (city)."
11. "Are you reaching out to (city) doctors? They're the ones who don't get it. Those are the doctors who should come to your meeting."

12. "The reason people are addicted to drugs is because they were not treated properly in the first place, so they sought out something to take care of that pain."
13. "You can die from brain disease and you can die from sickle cell disease, but we are put below it. Professionals do not see sickle cell disease as life threatening."
14. "We don't wear our symptoms like people with cancer."
15. "We were born with this. Our parents had the trait or the disease. We did not have a choice."
16. "I would rather have a baby than have a sickle cell crisis."
17. "People need to know the importance of donating blood for sickle cell disease. I've gotten so many blood transfusions, that my doctors have to look all over to find blood for me. It can take 3-4 days. I've built up different antibodies so it makes transfusions difficult."
18. "I'm a first time parent of a child with sickle cell. Education is very important."
19. "It's not a one day disease, it's a life-long disease."
20. "Last July there was blood drive with Red Cross specifically for sickle cell. It was great because it only focused on sickle cell. Part of the blood drive was to test people for whether or not they had the trait."
21. "(Hematologist) is the best."
22. "I see (doctor). I like him a lot."
23. "I'm happy with my care at (hospital)."
24. "I tell people to get in contact with (doctor) because he knows what he's doing and they (doctors) do not."

VII. Conclusions

It was beneficial to hear different factors that play a role in SCD, as it emphasized how multi-faceted the disease is. The focus group discussions generated a variety of discussion topics for the MDCH Sickle Cell Disease Strategic Planning Meeting held October 13, 2014 and issues that will inform the overall plan. Doctors, nurses, public health professionals, individuals living with SCD and their family members from around the state attended the meeting. The meeting began with a general overview about sickle cell and the disease burden, and concluded with workgroup breakout sessions, where attendees discussed topics relevant to SCD (i.e. transition of care, medication compliance, research, public education and awareness, day treatment centers, public/private insurance issues, and psychosocial/mental health. The next step is to gather the information accrued from the Strategic Planning Meeting and generate objectives and points of action to develop an MDCH Sickle Cell Disease Strategic Plan.

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